
VIII Annual Symposium on Biomedicine, Ethics and Society: “Rethinking Informed Consent: The limits of autonomy”

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Informed Consent and Autonomy

Present day informed consent acts as a safeguard against any abuse and delusion of research subjects in medical research. The extreme brutality and disrespect towards the research subjects in the Nazi experiments, led the Nuremberg Code of 1947 to state the principle of voluntary consent by the research subject as “absolutely essential” to all kinds of medical research. Later revelations of abuse and delusion of research subjects both in Europe and in North America led to increased focus on the need for informed consent by participants in medical research. Informed consent thus protects the research subjects from harm – it protects their *negative freedom*.

During the last decades, there has also been a major change in the relationship between the patient and the doctor. The ideal of autonomy has gained ground in health care, as well as in society at large. Informed consent is thus also a safeguard against undue paternalism in health care. The rationale of informed consent is thus both to protect the negative freedom of the individual not to be harmed as a research participant, and to promote the *positive freedom* to express preferences in how to be treated as a patient. The ideal is that any involvement with health care and medical research reflects the autonomous decision of the individual concerned.

What is the relationship between informed consent, and respect for autonomy? Beauchamp and Childress state in their *Principles of Biomedical Ethics* that “since the mid-1970s the primary justification advanced for requirements of informed consent has been to protect autonomous choice”. Against this, James Stacey Taylor holds in *Autonomy and Informed Consent* that “the doctrine of informed consent is based on the value of patient well-being instead of the value of patient autonomy”, and Mary Warnock wants in *Informed Consent – a publishers duty* to exchange the reference to the principle of autonomy in justifications of informed consent with “the more precise title of the principle of non-exploitation”.

This paper will discuss the role of autonomy in the ethical justification of informed consent requirements in medical research. Is the ultimate aim of informed consent not autonomy, but human well-being? Is the aim of informed consent to respect the autonomy of the research participants (avoid to deceive or coerce them), *in order to* promote their well-being (avoid harm by giving incomplete or confusing information)? A discussion of the relation between autonomy and moral duty will draw upon the works of Onora O’Neill, Harry Frankfurt and Charles Taylor: If the exercise of one’s autonomy implies a duty to make strong evaluations – does this point towards a duty to promote health in general?